



CHILDREN'S MERCY BIOETHICS CENTER
CERTIFICATE PROGRAM IN PEDIATRIC BIOETHICS
--- 2020 - 2021 Program Syllabus ---

Readings

Readings are required unless noted as "Other Suggested Readings" which are optional.

Online Discussion

Students are required to participate in the weekly online discussion. Students are allowed one non-participation week per semester.

Webinars & Podcasts

The Bioethics Center will host numerous podcasts (Pediatric Ethics Podcast), CMBC webinars and three program-specific webinars. Each student must attend (or watch the taped recording of) six webinars and/or listen to podcasts and must attend (or watch the taped recording of) all program-specific webinars, for a total of nine. Students who are not able to attend live webinars will participate in an online discussion of the webinar to fulfill the requirement. The webinar schedule will be distributed via email and posted to CourseSites. Webinar and Podcast requirement must be completed by April 2021.

Final Paper/Project Deadlines

The final paper/project is an important component of the Certificate Program. You will be working with one of the four core faculty (Angie, Brian, Jeremy, and John) who will assist in helping you narrow your topic as well as match you with additional faculty to work with. To help you stay on track, see timeline below.

- **Sept. 30:** List of 1-3 possible topics due to Jeremy Garrett.
- **Nov. 2:** Subject narrowed for final project. Jeremy Garrett will assign faculty mentor(s).
- **Dec. 11:** Topic/project picked. Abstract due.
- **Jan. 25:** Outline (or comparable product) due.
- **Mar. 8:** First project draft (or comparable product) due.
- **Apr. 5-16:** Practice presentations.
- **Apr. 30:** Second project draft (or comparable product) due.
- **May 6-8:** Final project due with presentation.

**First Semester/FALL
(Sept. 11 – Dec. 22, 2020)**

**Certificate Program Opening Session Kansas City, MO
(September 11-13, 2020) – See *Opening Session Syllabus***

Weeks 1-9: Foundations

Week #1 Parental Authority (Sept. 16-22) - Brian Carter, Jill Beck, Larissa Hines, Matthew Schlageter

- Verkerk MA et al. [Where families and healthcare meet](#). *J Med Ethics*. 2015 Feb;41(2):183-5. doi: 10.1136/medethics-2013-101783. Epub 2014 Sep 10.
- Humikowski CA. [Confession](#). *Arch Pediatr Adolesc Med*. 2012 Jul 1;166(7):593-4. doi: 10.1001/archpediatrics.2012.28.
- Clark JD. [Balancing the tension: parental authority and the fear of paternalism in end-of-life care](#). (comment on "Confession"). *Arch Pediatr Adolesc Med*. 2012 Jul 1;166(7):594. doi: 10.1001/archpediatrics.2012.556.
- Groll D. [Four models of family interests](#). *Pediatrics*. 2014 Oct;134 Suppl 2:S81-6. doi: 10.1542/peds.2014-1394C.
- Caplan A, Folkers KM. [Charlie Gard and the Limits of Parental Authority](#). *Hastings Cent Rep*. 2017 Sep;47(5):15-16. doi: 10.1002/hast.772.
- Pyle AK, Fleischman AR, Hardart G, Mercurio MR. [Management options and parental voice in the treatment of trisomy 13 and 18](#). *J Perinatol*. 2018 Sep;38(9):1135-1143. doi: 10.1038/s41372-018-0151-6. Epub 2018 Jul 6.
- Groll, Daniel. [Balancing a Child's Interest With the Interests of Other Family Members](#). Children's Mercy Pediatric Ethics Podcast. 2020.

Other suggested reading:

- Noggle R. The Moral and Political Status of Children. Chapter 6: Special Agents - Children's Autonomy and Parental Authority. David Archard & Colin McLeod (Eds.). Oxford University Press (2002): 97-117. (posted on CourseSites)
- Smetana J et al. [Adolescents' and parents' changing conceptions of parental authority](#). *New Dir Child Adolesc Dev*. 2005 Summer;(108):31-46. (posted to CourseSites)
- Mercurio MR. [Parental authority, patient's best interest and refusal of resuscitation at borderline gestational age](#). *J Perinatol*. 2006 Aug;26(8):452-7.
- AJ Alessandri. [Parents know best: Or do they? Treatment refusals in paediatric oncology](#). *J Paediatr Child Health*. 2011; 47:628-631. doi:10.1111/j.1440-1754.2011.02170.x

Week #2 → Parental Consent and Pediatric Assent (Sept. 23-29) - John Lantos, Larissa Hines, Donna McKlindon, DeeJo Miller, Doug Myers

Revised March 2021

- Katz AL, Webb SA, AAP COMMITTEE ON BIOETHICS. [Informed Consent in Decision-Making in Pediatric Practice](#). *Pediatrics*. 2016;138(2):e20161485.
- Unguru Y. Pediatric decision-making: informed consent, parental permission, and child assent. *Clinical Ethics in Pediatrics A Case Based Textbook*. Cambridge: Cambridge University Press; 2011, pages 1-6. (posted on CourseSites)
- Janvier A, Barrington K, Farlow B. [Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology](#). *Semin Perinatol*. 2014 Feb;38(1):38-46. doi: 10.1053/j.semperi.2013.07.007.

Other suggested reading:

- Unguru Y et al. Rethinking pediatric assent: from requirement to ideal. *Pediatr Clin North Am*. 2008 Feb;55(1):211-22, xii. doi: 10.1016/j.pcl.2007.10.016.

Week #3 → Best Interest Standard (Sept. 30 – Oct. 6) - Jeremy Garrett, Larissa Hines, DeeJo Miller, Laura Murkin, Erin Thomasma

- Kopelman LM. [The best-interests standard as threshold, ideal, and standard of reasonableness](#). *J Med Philos*. 1997 Jun;22(3):271-89.
- Salter EK. [Deciding for a child: a comprehensive analysis of the best interest standard](#). *Theor Med Bioeth*. 2012 Jun;33(3):179-98. doi: 10.1007/s11017-012-9219-z.
- Malek J. [What really is in a child's best interest? Toward a more precise picture of the interests of children](#). *J Clin Ethics*. 2009 Summer;20(2):175-82.

Other suggested reading:

- Blustein J. [Doing the best for one's child: satisficing versus optimizing parentalism](#). *Theor Med Bioeth*. 2012 Jun;33(3):199-205. doi: 10.1007/s11017-012-9222-4.
- Kopelman LM. Using the Best-Interests Standard in Treatment Decisions for Young Children. In: Miller (ed.), *Pediatric Bioethics*. Cambridge: Cambridge University Press, 2010, pp. 22-27. (posted on CourseSites)
- Griffith R. [Determining what is in the best interests of a critically ill child](#). *Br J Nurs*. 2013 Jan 24-Feb 13;22(2):112-3.
- De Vries MC et al. [What Constitutes the Best Interest of a Child? Views of Parents, Children, and Physicians in a Pediatric Oncology Setting](#). *AJOB Primary Research*. 2013. 4:2, 1-10, DOI: 10.1080/21507716.2012.757254. (posted on CourseSites)

Week #4 → Harm Principle/Open Future (Oct. 7-13) - Jeremy Garrett, Larissa Hines, Laura Murkin, Hank Puls

- Lombrozo T. NPR Commentary: ["Why do we judge parents for putting kids at perceived—but unreal—risk?"](#) August 22, 2016.

- Diekema S. Parental refusals of medical treatment: the harm principle as threshold for state intervention. *Theoretical Medicine and Bioethics*. 2004;25(4):243-264. (posted on CourseSites) *Note: only pp. 243-254 are required; the rest is suggested.*
- Wilkinson D, Nair T. [Harm isn't all you need: parental discretion and medical decisions for a child](#). *J Med Ethics*. 2016 Feb;42(2):116-8. doi: 10.1136/medethics-2015-103265. Epub 2015 Dec 18
- Garrett JR. [Prologomena to Any Future Pediatric Bioethics](#). *American Journal of Bioethics*. 2018;18(8):63-65.
- Garrett JR, et al. [Rethinking the "open future" argument against predictive genetic testing of children](#). *Genet Med*. 2019 Mar 21. doi: 10.1038/s41436-019-0483-4.
- Jeremy Garrett. [Right to an Open Future](#). *Pediatric Ethics Podcast*. 2020.

Other suggested reading:

- Thomas AJ, Stanford PK, Sarnecka BW. [No child left alone: moral judgments about parents affect estimates of risk to children](#). *Collabra*. 2016;2(1):10,1-4.
- Gillam, L. [The zone of parental discretion: an ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child](#). *Clinical Ethics*. December 18, 2015
- Feinberg J. The child's right to an open future. Chapter Three of *Freedom and Fulfillment: Philosophical Essays*. Princeton, NJ: Princeton University Press, 1992. (posted on CourseSites) *Note: emphasize pp. 76-78.*
- Davis DS. [Genetic dilemmas and the child's right to an open future](#). *Hastings Cent Rep*. 1997 Mar-Apr;27(2):7-15.
- Bredenoord AL et al. [The right to an open future concerning genetic information](#). *Am J Bioeth*. 2014;14(3):21-3. doi: 10.1080/15265161.2013.879952.

Week #5 → Personal Conscience (Oct. 14-20) – Jeremy Garrett, Laura Murkin, Cathy Shubkin, Ian Wolfe

- Sulmasy DP. [What is conscience and why is respect for it so important?](#) *Theor Med Bioeth*. 2008;29(3):135-49. doi: 10.1007/s11017-008-9072-2.
- McCullough LB. [Review of Mark R. Wicclair, Conscientious Objection in Health Care: An Ethical Analysis](#). *Notre Dame Philosophical Reviews*. 2012.09.22.
- AAP Committee on Bioethics. [Policy statement--Physician refusal to provide information or treatment on the basis of claims of conscience](#). *Pediatrics*. 2009 Dec;124(6):1689-93. doi: 10.1542/peds.2009-2222.

Other suggested reading/resources:

- [HHS Releases New Rule on Health Workers' Religious, Moral Objections](#). *Washington Post*. January 19, 2018.
- [Conscience Protections for Health Care Providers](#). HHS.gov.
- Daniel Sulmasy, OFM, MD, PhD: [The Role of Conscience in Medical Decisions](#). The Center for Practical Bioethics. (webinar)

Revised March 2021

- Wicclair MR. [Is conscientious objection incompatible with a physician's professional obligations?](#) *Theor Med Bioeth.* 2008;29(3):171-85. doi: 10.1007/s11017-008-9075-Z.
- Billharz, J. [Truth Telling Is It Ever Virtuous to Lie.](#) AAP Section on Bioethics Newsletter, Fall 2011. (posted on CourseSites)
- Giubilini, A. [Objection to Conscience: An Argument Against Conscience Exemptions in Healthcare.](#) *Bioethics.* 23 December 2016. DOI: 10.1111/bioe.12333.
- Liberman, A. [Wrongness, responsibility, and conscientious refusals in health care.](#) *Bioethics.* 2017 Apr 3. doi: 10.1111/bioe.12351. [Epub ahead of print]

Week #6 → Moral Distress (Oct. 21-27) - Angie Knackstedt, Dan Ballesteros, Dyane Bunnell, Charlotte Jacobsen, Charlotte Smardo, Laura Miller-Smith, Stacy Smith

- AACN. [Position Statement: Moral Distress in Times of Crisis.](#) March 25, 2020.
- Jameton A. [What Moral Distress in Nursing History Could Suggest about the Future of Health Care.](#) *AMA Journal of Ethics.* June 2017 19(6):617-628.
- McCarthy J., Monteverde S. [The Standard Account of Moral Distress and Why We Should Keep It.](#) *HEC Forum.* 2018. February 28. Doi:10.1007/s10730-01809349-4.
- Weber E. [Moral distress, workplace health, and intrinsic harm.](#) *Bioethics.* 2016 May;30(4):244-50. doi: 10.1111/bioe.12181. Epub 2015 Aug 26.
- Sauerland J. et al. [Assessing and Addressing Moral Distress and Ethical Climate Part II: Neonatal and Pediatric Perspectives.](#) *Dimens Crit Care Nurs.* Jan-Feb 2015. 34(1): 33 - 46.
- [Strategies for Addressing Moral Distress: An Interview with Dr. Elizabeth Epstein](#) (podcast). *AMA Journal of Ethics.* June 2017.

Other suggested reading:

- Epstein B, Hamric A. [Moral Distress, Moral Residue, and the Crescendo Effect.](#) *J Clin Ethics.* 2009. 20(4):330 – 342.
- Fourie C. [Who Is Experiencing What Kind of Moral Distress? Distinctions for Moving from a Narrow to a Broad Definition of Moral Distress.](#) *AMA J Ethics.* 2017 Jun 1;19(6):578-584. doi: 10.1001/journalofethics.2017.19.6.nlit1-1706.
- Gallagher A. [Moral distress and moral courage in everyday nursing practice.](#) *Online J Issues Nurs.* 2011 Mar 21;16(2):8.
- Chen, P. [When doctors and nurses can't do the right thing.](#) *The New York Times.* February 6, 2009.
- Morley G. [What is "moral distress" in nursing? How, can and should we respond to it?](#) *J Clin Nurs.* 2018. 27:3443-3445.
- Rushton CH et al. [CE: Moral distress: a catalyst in building moral resilience.](#) *Am J Nurs.* 2016 Jul;116(7):40-9. doi: 10.1097/01.NAJ.0000484933.40476.5b.
- [Ann Hamric, PhD, RN, FAAC: Moral Distress in Pediatric Intensive Care.](#) Children's Mercy Bioethics Center Webinar. January 27, 2017.

Week #7 → Professional Integrity and Obligations (Oct. 28 – Nov. 3) - Brian Carter, Donna McKlindon, Laura Miller-Smith, Laura Murkin, Brenda Rogers, Cathy Shubkin

- Mitchell LA. [Integrity and virtue: the forming of good character](#). *Linacre Q*. 2015 May;82(2):149-69. doi: 10.1179/2050854915Y.0000000001.
- Johnson. [Nursing Professionalism: Innate, taught, or caught?](#) *J Nurses Prof Dev*. Mar-Apr;31(2):114-5. doi: 10.1097/NND.000000000000149.
- Thomas TA et al. [A qualitative study exploring moral distress among pediatric resuscitation team clinicians: challenges to professional integrity](#). *Pediatr Crit Care Med*. 2016 Jul;17(7):e303-8. doi: 10.1097/PCC.0000000000000773.
- Brudney, D. [“Pregnancy is not a disease”: conscientious refusal and the argument from concepts](#). *Hastings Cent Rep*. 2014 Sep;44(5):43-9. doi: 10.1002/hast.357.
- Daniel Brudney. [Is Pregnancy a Disease? And Why Does That Matter](#). *Pediatric Ethics Podcast*. 2020.

Other suggested reading:

- Crigger N, Godfrey N. [From the inside out: a new approach to teaching professional identity formation and professional ethics](#). *J Prof Nurse*. 2014 Sep-Oct;30(5):376-82. doi: 10.1016/j.profnurs.2014.03.004. Epub 2014 Mar 28.
- Hillis DJ, Grigg MJ. [Professionalism and the role of medical colleges](#). *Surgeon*. 2015 Oct;13(5):292-9. doi: 10.1016/j.surge.2015.04.001. Epub 2015 Apr 27.
- Salloch S. [Same but different: why we should care about the distinction between professionalism and ethics](#). *BMC Med Ethics*. 2016 Jul 22;17(1):44. doi: 10.1186/s12910-016-0128-y.

Week #8 → Religious and Cultural Issues (Nov. 4-10) - Angie Knackstedt, Dan Ballesteros, Beth Clark, Charlotte Jacobsen, Terri Major-Kincade, DeeJo Miller, Sarosh Saleem, Matthew Schlageter, Dane Sommer, Erin Thomasma

- Desai et al. [Latino caregiver coping with children’s chronic health conditions: an integrative literature review](#). *J Pediatr Health Care*. 2016 Mar-Apr;30(2):108-20. doi: 10.1016/j.pedhc.2015.06.001. Epub 2015 Jul 15.
- Kass NE. [Ethics, Refugees, and the President’s Executive Order](#). *Am J Bioeth*. 2017 May;17(5):4-5. doi: 10.1080/15265161.2017.1301139.
- Kotalik J, Martin G. [Aboriginal Health Care and Bioethics: A Reflection on the Teaching of the Seven Grandfathers](#). *Am J Bioeth*. 2016 May;16(5):38-43. doi: 10.1080/15265161.2016.1159749.
- Kruizinga MA et al. [Toward a Fully Fledged Integration of Spiritual Care and Medical Care](#). *J Pain Symptom Manage*. 2017. 55(3): 1035 – 1040.
- Page K. et al. [Undocumented U.S. Immigrants and COVID-19](#). *New England Journal of Medicine*. (NEJM.org). May 21, 2020. 382;21. e620(1-3).
- Smyre C, Tak HJ, Dang AP, Curlin FA, Yoon JD. [Physicians Opinions on Engaging Patient’s Religious and Spiritual Concerns: A National Survey](#). *J Pain Symptom*

Manage. 2018 Mar;55(3):897-905. doi: 10.1016/j.jpainsymman.2017.10.015. Epub 2017 Nov 1.

- Zaidi D. [Influences of Religion and Spirituality in Medicine](#). *AMA American Journal of Ethics*. July 2018. 20(7): E609-612.
- 'You are not alone': Chaplains provide emotional support to COVID-19 Patients. (ABC News) <https://abcnews.go.com/Politics/chaplains-provide-emotional-support-covid-19-patients/story?id=69944797>

Other suggested reading:

- NPR. [Boy On Life Support Stirs Debate On Faith, End-Of-Life Care](#). Nov. 14 2008.
- [Parent Voices: Hope and Faith in the Midst of Illness](#). Seattle Children's (video).
- Puchalski CM et al. [Physicians and patients' spirituality](#). *Virtual Mentor*. 2009 Oct 1;11(10):804-15. doi: 10.1001/virtualmentor.2009.11.10.oped1-0910.
- Culley L. [Transcending transculturalism? Race, ethnicity and health-care](#). *Nurs Inq*. 2006 Jun;13(2):144-53.
- Schaffer, A. [How Jehovah's Witnesses are changing medicine](#). *The New Yorker*. August 12, 2015.
- Sulmasy DP. [Distinguishing denial from authentic faith in miracles: a clinical-pastoral approach](#). *South Med J*. 2007 Dec;100(12):1268-72.
- Wein S. [Spirituality--the psyche or the soul?](#) *Palliat Support Care*. 2014 Apr;12(2):91-4. doi: 10.1017/S1478951514000303.
- Wiener L et al. [Cultural and religious considerations in pediatric palliative care](#). *Palliat Support Care*. 2013 Feb;11(1):47-67. doi: 10.1017/S1478951511001027. Epub 2012 May 22.

Week #9 → Justice and Allocation (Nov. 11-17) - Jeremy Garrett, Amy Caruso Brown, Charlotte Jacobsen, Laura Murkin

- Diekema, D. [Is there an Ethical Obligation to Provide Healthcare to All Children?](#) Seattle Children's Pediatric Bioethics Conference July 22-23, 2011.
- [Amy Caruso Brown, MD, MSc, MSCS: Is Being Treated at a Children's Hospital a Right or a Privilege?](#) Children's Mercy Bioethics Center (webinar). May 10, 2018.
- Eyssalenne, AP. [How far do you go? Intensive care in a resource-poor setting](#). *New England Journal of Medicine*. 2012;367(1):8-9.
- Boss RD, Henderson CM, Wilfond BS. [Decisions regarding resuscitation of extremely premature infants: should social context matter?](#) *JAMA Pediatrics*. 2015;169(6):521-522.
- Binkley CE, Kemp DS. [Ethical rationing of personal protective equipment to minimize moral residue during the COVID-19 pandemic](#). *Journal of the American College of Surgeons*. 2020 Jun;230(6):1111-1113. doi: 10.1016/j.jamcollsurg.2020.03.031. Epub 2020 Apr 9.
- Haward MF, Moore GP, Lantos J, Janvier A. [Paediatric ethical issues during the COVID-19 pandemic are not just about ventilator triage](#). *Acta Paediatrica*. 2020 May 4;10.1111/apa.15334. doi: 10.1111/apa.15334.

Revised March 2021

- Churchill LR, King NMP, Henderson GE. [The future of bioethics: it shouldn't take a pandemic](#). *Hastings Center Report* 2020;50(3):54-56.
- Hardeman RR, Medina EM, Boyd RW. [Stolen breaths](#). *New England Journal of Medicine*. 2020. Jun 10. doi: 10.1056/NEJMp2021072. Online ahead of print.

Other suggested reading:

- Mosely KL & Kershaw DB. [African American and white disparities in pediatric kidney transplantation in the United States -- unfortunate or unjust?](#) *Cambridge Quarterly of Healthcare Ethics*. 2012;21:353-365.
- Wightman A, Largent E, Del Beccaro M, Lantos JD. [Who Should Get the Last PICU Bed?](#) *Pediatrics*. 2014 Apr 28. [Epub ahead of print].
- Ubel PA. [Why it's not time for health care rationing](#). *Hastings Center Report*. 2015;45(2):15-19.
- Blinderman C. [Palliative care, public health and justice: setting priorities in resource poor countries](#). *Developing World Bioethics*. 2009;9(3):105-110.
- Hendriks MJ, Lantos JD. [Fragile lives with fragile rights: justice for babies born at the limit of viability](#). *Bioethics*. 2018;32(3):205-214.
- Beck JC, Smith LD, Gordon BG, Garrett JR. [An ethical framework for responding to drug shortages in pediatric oncology](#). *Pediatr Blood Cancer*. 2015;62:931-934.

Week #10 → Intersection of Ethics, Society, Health Equity and Health Care Policy (Nov. 18-24) - Angie Knackstedt, Amy Caruso Brown, Beth Clark, Denise Dowd, Charlotte Jacobsen, Terri Major-Kincade, Soo Shim, Vince Staggs, Vanessa Watkins, Susie Wootton

- Berwick, DM. [The Moral Determinants of Health](#). *JAMA*. published online June 6, 2020. Doi: 10.1001/jama.2020.1129
- American Academy of Pediatrics Board of Directors. [Truth, Reconciliation, and Transformation: Continuing the Path to Equity](#). September 2020. 14(3): e2020019794. doi:10.1542/peds2020-019794.
- AAP Policy Statement. [Community Pediatrics: Navigating the Intersection of Medicine, Public Health, and Social Determinants of Children's Health](#). DOI: 10.1542/peds.2012-3933 *Pediatrics* 2013;131:623; originally published online February 25, 2013.
- Haggerty J et al. [Proactive Strategies to Address Health Equity and Disparities: Recommendations from a Bi-National Symposium](#). *J Am Board Fam Med*. 2018 May-Jun;31(3):479-483. doi: 10.3122/jabfm.2018.03.170299.
- Specker Sullivan L. [Trust, Risk and Race in American Medicine](#). *Hasting Center Report*. 2020. 50(1): 18-26. doi:10.1002/hast.1080.

- Mohottige D., Bouware L.E. [Trust in American Medicine: A Call to Action for Health Care Professionals](#). Hasting Center Report. 2020. 50(1): 27-29. doi: 101002/hast.1081.
- Thornton, RL et al. [Evaluating Strategies for reducing health disparities by addressing the social determinants of health](#). *Health Aff (Millwood)*. 2016 Aug 1;35(8):1416-23. doi: 10.1377/hlthaff.2015.1357.
- TedMed Talk. [Nadine Burke Harris: How childhood trauma affects health across a lifetime](#). September 12, 2014.

Other suggested reading:

- Braveman P. [What are health disparities and health equity? We need to be clear](#). *Public Health Rep*. 2014 Jan-Feb;129 Suppl 2:5-8.
- Braveman PA, Kumanyika S, Fielding J, Laveist T, Borrell LN, Manderscheid R, Troutman A. [Health disparities and health equity: the issue is justice](#). *Am J Public Health*. 2011 Dec;101 Suppl 1:S149-55. doi: 10.2105/AJPH.2010.300062. Epub 2011 May 6.
- Frieden TR. [Shattuck Lecture: The Future of Public Health](#). *N Engl J Med*. 2015 Oct 29;373(18):1748-54. doi: 10.1056/NEJMsa1511248.
- Hall M, Graffunder C, Metzler M. [Policy Approaches to Advancing Health Equity](#). *J Public Health Manag Pract*. 2016 Jan-Feb;22 Suppl 1:S50-9. doi: 10.1097/PHH.0000000000000365.
- Ted2017. [Raj Punjani: Illness is universal, but access to healthcare is not \(video\)](#). April 2017.
- Srinivasan S, Williams SD. [Transitioning from Health Disparities to a Health Equity Research Agenda: The Time Is Now](#). *Public Health Rep*. 2014 Jan-Feb. 129 (Suppl 2): 71 – 76.
- TedMed Talk. [Rebecca Onie: What if our healthcare system kept us healthy \(video\)](#). June 12, 2012.

Thanksgiving Break → Nov. 25 – Dec. 1

Week #11 → Ethics Consultation (Dec. 2-8) - Brian Carter, Jeremy Garrett, Angie Knackstedt, John Lantos

- Bruce CR. Case study. [Consultations across Languages](#). Commentary. *Hastings Cent Rep*. 2015 May-Jun;45(3):14.
- Førde R, Linja T. ["It scares me to know that we might not have been there!": a qualitative study into the experiences of parents of seriously ill children participating](#)

[in ethical case discussions](#). *BMC Med Ethics*. 2015 Jun 6;16:40. doi: 10.1186/s12910-015-0028-6.

- Pearlman RA, Foglia MB, Fox E, Cohen JH, Chanko BL, Berkowitz KA. [Ethics Consultation Quality Assessment Tool: A Novel Method for Assessing the Quality of Ethics Case Consultations Based on Written Records](#). *Am J Bioeth*. 2016;16(3):3-14. doi: 10.1080/15265161.2015.1134704.
- Tarzian AJ, Wocial LD; ASBH Clinical Ethics Consultation Affairs Committee. [A code of ethics for health care ethics consultants: journey to the present and implications for the field](#). *Am J Bioeth*. 2015;15(5):38-51. doi: 10.1080/15265161.2015.1021966.

Review Reading Assigned from Opening Session:

- Bruce CR, Smith ML, Tawose OM, Sharp RR. [Practical guidance for charting ethics consultations](#). *HEC Forum*. 2014 Mar;26(1):79-93. doi: 10.1007/s10730-013-9228-y.

Week #12 → Critical Analysis: Ethics Consultation (Dec. 9-15) - Brian Carter, Jeremy Garrett, Angie Knackstedt, John Lantos

Week #13 → International Medicine: Clinical and Research Realities (Dec. 16-22)
John Lantos, Siri Berg, Austin Dalgo, Monica Hendricks, Azanna Kamar, Erwin Khoo, Sarosh Saleem

- Berkowitz AL. [A Piece of My Mind: All for One](#). *JAMA*. 2015 Oct 6;314(13):1341-2. doi: 10.1001/jama.2015.4888.
- Farmer, P. From “Marvelous Momentum” to Health Care for All. *Foreign Affairs*. Mar/Apr 2007, Vol 86 Issue 2. P 155-159. 5 p. (posted on CourseSites)
- Bradley S et al. [Too few staff, too many patients: a qualitative study of the impact on obstetric care providers and on quality of care in Malawi](#). *BMC Pregnancy Childbirth*. 2015 Mar 21;15:65. doi: 10.1186/s12884-015-0492-5.
- Melby MK et al. [Beyond Medical “Missions” to Impact-Driven Short-Term Experiences in Global Health \(STEGHs\): Ethical Principles to Optimize Community Benefit and Learner Experience](#). *Acad Med*. 2016 May;91(5):633-8. doi: 10.1097/ACM.000000000000100.

Other suggested readings:

- Kavanagh, MM et al. [Access to Lifesaving Medical Resources for African Countries: COVID-19 Testing and Response, Ethics, and Politics](#). *Lancet*. 2020 30 May-5 June;395(10238): 1735–1738. Published online 2020 May 7. doi: 10.1016/S0140-6736(20)31093-X.
- Kramer JB et al. [Ethics in the Time of Coronavirus: Recommendations in the COVID-19 Pandemic](#). *J Am Coll Surg*. 2020 Jun; 230(6): 1114–1118. Published online 2020 Apr 9. doi: 10.1016/j.jamcollsurg.2020.04.004

- Blinderman C. [Palliative care, public health and justice: setting priorities in resource poor countries](#). *Dev World Bioeth*. 2009 Dec;9(3):105-10. doi: 10.1111/j.1471-8847.2009.00264.x. Epub 2009 Oct 7.
- Carnevale FA, Manjavidze I. [Examining the complementarity of 'children's rights' and 'bioethics' moral frameworks in pediatric health care](#). *J Child Health Care*. 2015 Dec 10. pii: 1367493515605173. [Epub ahead of print]
- Almazeedi, H. [What Money Can Buy](#). *Pulse Voices*. Friday, April 8, 2016.

Winter Break → Dec. 23 – Jan. 5

**Second Semester/SPRING
(Jan. 6 – May 8, 2021)**

Weeks 14-17: Critical Care & End of Life

Short Stories Webinar → The Aquarium (Hemon) and People Like That Are the Only People Here (Moore) – January 6 9-10 a.m. via CourseSites - Core/Subject Faculty

Week #14 → Brain Death, Minimal Consciousness, and Vegetative States (Jan. 6 - 12) - Brian Carter, John Lantos, Matt Mayer, Laura Miller-Smith, Dane Sommer

- Shah SK, Truog RD, Miller FG. [Death and legal fictions](#). *J Med Ethics*. 2011 Dec;37(12):719-22. doi: 10.1136/jme.2011.045385. Epub 2011 Aug 2.
- Gardiner D, Shemie S, Manara A, Opdam H. [International perspective on the diagnosis of death](#). *Br J Anaesth*. 2012 Jan;108 Suppl 1:i14-28. doi: 10.1093/bja/aer397.
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Weeks 18-21: Special Issues in Pediatrics

Weeks #18 → Adolescents and Health Care (Feb. 3-9) - Angie Knackstedt, Beth Clark, Laurie Hornberger, DeeJo Miller, Brenda Rogers, Cathy Shubkin, Stacy Smith

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Week #19→ Reproductive and Fetal Medicine (Feb. 10-16) - Brian Carter, Jennifer Gannon, Jennifer Kussman, Meghan Strenk

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Week #20 → Child Abuse and Neglect (Feb. 17-23) - John Lantos, Larissa Hines, Hank Puls, Erin Thomasma, Andrea Vandeven

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Week #21 → Complex Pediatric Care (Feb. 24 – Mar. 2) - Brian Carter, Angie Knackstedt, Dyane Bunnell, Beth Condley, Gary Lerner, Glen Medellin, DeeJo Miller, Charlotte Smardo

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Week 22 → Mental Health (Mar. 3-9) - Angie Knackstedt, Dyane Bunnell, Mary Anne Hammond, Laura Miller-Smith, DeeJo Miller, Gail Robertson, Erin Thomasma

- COUNCIL ON EARLY CHILDHOOD; COMMITTEE ON PSYCHOSOCIAL ASPECTS OF CHILD AND FAMILY HEALTH; SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS. [Addressing Early Childhood Emotional and Behavioral Problems](#). *Pediatrics*. 2016 Dec;138(6). pii: e20163023.
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Weeks 23-24 Research Ethics

Week #23 → Research Ethics (Mar. 10-16) - Jeremy Garrett, John Lantos, Gayla Goleman, DeeJo Miller, Dane Sommer, Vince Staggs

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- Gutmann A. [Safeguarding Children—Pediatric Research on Medical Countermeasures.](#) *N Engl J Med.* 2013 Mar 28;368(13):1171-3. doi: 10.1056/NEJMp1302093. Epub 2013 Mar 19.

- Menikoff J, Kaneshiro J, Pritchard I. [The Common Rule, Updated](#). *N Engl J Med*. 2017 Feb 16;376(7):613-615. doi: 10.1056/NEJMp1700736. Epub 2017 Jan 19.
- DeGrazia D, Groman M, Lee LM. [Defining the Boundaries of a Right to Adequate Protection: A New Lens on Pediatric Research Ethics](#). *J Med Philos*. 2017 Feb 10. doi: 10.1093/jmp/jhw038. [Epub ahead of print]

Week #24 → Pediatric Genetics and Newborn Screening (Mar. 17-23) - Jeremy Garrett, John Lantos, Michael Deem, Jennifer Gannon, Meghan Strenk, Soo Shim

- Bailey D, Gehtland L. [Newborn Screening: Evolving Challenges in an Era of Rapid Discovery](#). *JAMA*. 2015;313(5):1511-1512.
- Kemper AR et al. [Weighing the evidence for newborn screening for early-infantile Krabbe disease](#). *Genetics in Medicine*. 2010;12(9):539-542.
- Hewlett J, Waisbren SE. [A review of the psychosocial effects of false-positive results on parents and current communication practices in newborn screening](#). *J Inherit Metab Dis*. 2006;29:677–682.
- AAP. [Ethical and policy issues with genetic testing and screening of children](#). *Pediatrics*. 2013.
- Newson AJ, Schonstein L. [Genomic Testing in the Paediatric Population: Ethical Considerations in Light of Recent Policy Statements](#). *Mol Diagn Ther*. 2016 Oct;20(5):407-14. doi: 10.1007/s40291-016-0210-7.
- Lainie Friedman Ross. [Targeted versus Universal Screening: The Role of Race in Genetic Policies and Practices](#). Seattle Children’s Pediatric Bioethics Conference July 20-21, 2018.

Other suggested reading:

- Kwame Anthony Appiah. [Can I Tell My Brother the Truth About our Paternity?](#) *The New York Times Magazine*. Sept. 3, 2018.

Spring Break → Mar. 24-30

Week #25 → Critical Analysis: Research (Mar. 31-Apr, 6) - Brian Carter, Jeremy Garrett, Angie Knackstedt, John Lantos

Final Project Practice Presentations (Apr. 7 - 20) Each student will present their draft paper/presentation for feedback with faculty advisor(s)

Book Webinar → *The Spirit Catches You and You Fall Down* – April 22 10-11 a.m. via CourseSites – Core/Subject Faculty

Weeks 26-27: More Special Issues in Pediatrics

Week #26 → Immunizations (Apr. 21-27) - Angie Knackstedt, Michael Deem, Laura Murkin, Brenda Rogers, Cathy Shubkin, Vince Staggs, Vanessa Watkins, Susie Wootton

- Frader J, Flanagan-Klygis E. Ethics and Immunizations. In: Miller (ed.), *Pediatric Bioethics* (pp. 219-230). (posted on CourseSites)
- Larson H. [The biggest pandemic risk? Viral misinformation](#). *Nature*. October 16, 2018.
- Lo NC, Hotez PJ. [Public Health and Economic Consequences of Vaccine Hesitancy for Measles in the United States](#). *JAMA Pediatr*. 2017 Jul 24. doi: 10.1001/jamapediatrics.2017.1695. [Epub ahead of print]
- O'Leary ST. et al. [Characteristics of Physicians Who Dismiss Families for Refusing Vaccines](#). *Pediatrics*. 2015 Dec. 136(6):1103-11. doi: 10.1542/peds.2015-2086.
- Politi MC, Jones KM, Philpott SE. [The Role of Patient Engagement in Addressing Parents' Perceptions About Immunizations](#). *JAMA*. 2017 Jul 18;318(3):237-238. doi: 10.1001/jama.2017.7168.
- Opel DJ et al. [Achieving an Optimal Childhood Vaccine Policy](#). *JAMA Pediatr*. 2017 Jul 3. doi: 10.1001/jamapediatrics.2017.1868. [Epub ahead of print]
- Deem M, Navin M, Lantos J. [Considering Whether the Dismissal of Vaccine-Refusing Families Is Fair to Other Clinicians](#). *JAMA Pediatr*. 2018 Jun 1;172(6):514-516. doi: 10.1001/jamapediatrics.2018.0259.
- Paules CI, Marston HD, Fauci AS. [Measles in 2019 - Going Backward](#). *N Engl J Med*. 2019 Jun 6;380(23):2185-2187. doi: 10.1056/NEJMp1905099. Epub 2019 Apr 17.
- Ault A. [What to Do When a Minor Seeks Vaccination Without Consent?](#) *Medscape*. February 20, 2019.

Other suggested reading/resources:

- Edwards KM, Hackell JM; COMMITTEE ON INFECTIOUS DISEASES, THE COMMITTEE ON PRACTICE AND AMBULATORY MEDICINE. [Countering Vaccine Hesitancy](#). *Pediatrics*. 2016 Sep;138(3). pii: e20162146. doi: 10.1542/peds.2016-2146.
- Alexander K, Lacy TA, Myers AL, Lantos JD. [Should Pediatric Practices Have Policies to Not Care for Children With Vaccine-Hesitant Parents?](#) *Pediatrics*. 2016 Oct;138(4). pii: e20161597. Epub 2016 Sep 2.
- Navin MC. [The Ethics of Vaccination Nudges in Pediatric Practice](#). *HEC Forum*. 2017 Mar;29(1):43-57. doi: 10.1007/s10730-016-9311-2.
- Lantos JD, Jackson MA, Harrison CJ. [Why we should eliminate personal belief exemptions to vaccine mandates](#). *J Health Polit Policy Law*. 2012 Feb;37(1):131-40. doi: 10.1215/03616878-1496038. Epub 2011 Oct 14.

- Anderson EJ, Daugherty MA, Pickering LK, Orenstein WA, Yogev R. [Protecting the Community Through Child Vaccination](#). *Clin Infect Dis*. 2018 Jul 18;67(3):464-471. doi: 10.1093/cid/ciy142.
- Deem M. [Responding to Parents Who Refuse Childhood Immunizations](#). *Nursing*. 47(12): 11-14. 2017 Dec;47(12):11-14. doi: 10.1097/01.NURSE.0000526899.00004.b9.
- Schwartz JL, Caplan AL. [Vaccine refusal: ethics, individual rights and the common good](#). *Prim Care*. 2011 Dec. 38(4):717-28, ix. doi: 10.1016/j.pop.2011.07.009. Epub 2011 Sep 17.

Week 27 → Communication Frontiers: Social Media (Apr. 28-May 4) - Angie Knackstedt, Amy Caruso Brown, Charlotte Jacobsen, DeeJo Miller, Donna McKlindon, Bry Moore, Vanessa Watkins

- McKlindon D et al. [Ethics Rounds: In the Eye of a Social Media Storm](#). *Pediatrics*. 2016;138(3). pii: e20161398. doi: 10.1542/peds.2016-1398. Epub 2016 Aug 5.
- Caruso Brown AE. [Porous Boundaries](#). *JAMA*. 2017 Jun 27;317(24):2487-2488. doi: 10.1001/jama.2017.1589.
- Parsi K, Elster N. [Why Can't We Be Friends? A Case-Based Analysis of Ethical Issues with Social Media in Health Care](#). *AMA J Ethics*. 2015 Nov 1;17(11):1009-18. doi: 10.1001/journalofethics.2015.17.11.peer1-1511.
- Snyder J. [Crowdfunding FOR MEDICAL CARE: Ethical Issues in an Emerging Health Care Funding Practice](#). *Hastings Cent Rep*. 2016 Nov;46(6):36-42. doi: 10.1002/hast.645.
- Terrasse M, Gorin M, Sisti D. [Social Media, E-Health, and Medical Ethics](#). *Hastings Cent Rep*. 2019 Jan;49(1):24-33. doi: 10.1002/hast.975.
- Waller M, Taylor L, Portnoy J. [The Medical Virtualist: Is Pediatric Patient Care Using Telemedicine, a New Specialty?](#) *Pediatr Ann*. 2019 Jun 1;48(6):e243-e248. doi: 10.3928/19382359-20190520-01.
- Camila Domonoske. [Texas Nurse Loses Job after Apparently Posting about Patient in Anti-Vaxxer Group](#). *NPR*. August 29, 2018.

Other suggested reading/resources:

- Gage-Bouchard EA, LaValley S, Mollica M, Beaupin LK. [Cancer Communication on Social Media: Examining How Cancer Caregivers Use Facebook for Cancer-Related Communication](#). *Cancer Nurs*. 2017 Jul/Aug;40(4):332-338. doi: 10.1097/NCC.0000000000000418.
- Buppert C. [Nurses and Social Media: Guard Your Career and your Reputation](#). *Medscape*. 2018 February 13.
- Booker CL, Kell YJ, Sacker A. [Gender differences in the associations between age trends of social media interaction and well-being among 10–15 year olds in the UK](#). *BMC Public Health*. 2018. 2018 Mar 20;18(1):321. doi: 10.1186/s12889-018-5220-4.

- Brauser D. Clinicians Warned about Social Media #Boundary Violations. Medscape. June 12, 2019. <https://www.medscape.com/viewarticle/914285>
- Azer SA. [Social Media Channels in Health Care Research and Rising Ethical Issues](#). *AMA J Ethics*. 2017 Nov 1;19(11):1061-1069. doi: 10.1001/journalofethics.2017.19.11.peer1-1711.
- Microsoft. [Children's Mercy app brings doctors home, virtually, with babies born with heart disease](#). July 20, 2016 (YouTube video discussing CM CHAMP (Cardiac High Acuity Monitoring Program)).
- Bala, Aparna. [How Technology Is Changing Nursing: The Impact of Telehealth](#). Medscape. July 28, 2017.

**Certificate Program Closing Session Kansas City, MO
(May 6-8, 2021) – See Closing Session Syllabus**